

வட மாகாணத்துக்கான ஒட்டிசம் கொள்கை Autism Policy for the Northern Province 2017-2022

வரைபு



சுகாதார, சுதேச மருத்துவ, நன்னடத்தை, சிறுவர் பராமரிப்பு சேவைகள் அமைச்சு
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வடக்கு மாகாணம்



This policy acknowledges the heterogeneity of Autism Spectrum Disorder (ASD) and the variety of ways in which it affects those with ASD and the people who care for them. In this document, *autism* is used interchangeably with *ASD*. However, *autism* is the term most widely recognised in Sri Lanka.

இந்தக் கொள்கையானது ஓட்டிசம் மற்றும் அதனுடன் தொடர்புடைய நிலைமைகளுடைய விகற்பமான தன்மையையும், அந்நிலைமைகள் உடையவர்களையும், அவர்களது பராமரிப்பாளர்களையும் அவை பல வகைகளில் பாதிக்கின்றன என்பதனையும் ஏற்றுக் கொள்கிறது. இந்த ஆவணத்தில் ஓட்டிசம் என்ற சொல்லே ஓட்டிசத்துடன் தொடர்புடைய பல்வேறு நிலைமைகளைப் பற்றிக் குறிப்பிடவும் பயன்பட்டிருக்கிறது. இலங்கையில் ஓட்டிசம் என்ற சொல்லே மிகப்பரவலாக அங்கீகாரம் பெற்று, உபயோகிக்கப்படுகின்ற சொல்லாக இருக்கின்றது.

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மீளாய்வுக்கான திகதி: ஜனவரி 2022

2. Northern Province Autism Policy 2017-2022

2.1. Vision, mission and values

Vision

An inclusive province that uphold the rights and dignity of all individuals affected by autistic spectrum disorder by providing equitable access to appropriate services and holistic care to further development and wellbeing of society.

Mission

Provide effective services to the people of the Northern Province by implementing programmes developed collaboratively by stakeholders at all levels of society to empower individuals affected by autism spectrum disorder to actively participate in society and improve their quality of life.

Values

This policy has been formulated using a rights-based approach to ensure the dignity of individuals affected by ASD. The key values that underpin this policy are equity, compassion, inclusivity, collaboration, accountability, sustainability and adherence to national policies and guidelines within local capacity.

2.2. Policy objectives

1. To ensure clarity of vision and coordinated action in the improvement of the quality of life of individuals affected by autism spectrum disorder in the Northern Province.
2. To protect, promote and uphold the rights and dignity of individuals affected by autistic spectrum disorder.
3. To increase the capacity of health, education, social and other public services alongside civil society organizations to deliver appropriate support for individuals affected with autistic spectrum disorder, carers and support givers.
4. To include the needs of carers and support givers in the formulation of strategies to improve services available for individuals affected by autism spectrum disorder.
5. To increase awareness and reduce stigma around autism spectrum disorders.
6. To highlight the need to collect accurate data about the impact of autism spectrum disorders on societal health and the adequacy of services provided.

2.3. Thematic Areas

2.3.1. Awareness and sensitisation

Generally there is a lack of awareness and sensitisation on ASD in society. Negative perceptions about disability combined with a lack of support can exacerbate the effects of stigma, discrimination and social isolation. This can cause many difficulties for individuals with ASD, including creating barriers to accessing health services, education, employment and living in the community with dignity. Collaborative and bottom-up approaches to raise awareness and sensitisation among civil

society, carers and support-givers in the health, education and social care sectors is imperative to empower individuals affected by ASD.

Recommendations

1. Advocacy plans should be developed by a multidisciplinary group of stakeholders, including individual affected by ASD, at all levels of society and acknowledge the heterogeneous nature of ASD such as variation in intellectual and functional abilities.
2. The implementation of advocacy plans to raise awareness and sensitisation should include multimedia, such as radio, television, print, Internet and social media for maximum reach.
3. Advocacy programmes should address negative attitudes and belief systems that may exacerbate stigma, discrimination and social isolation and prevent equitable access to services and supports.
4. Advocacy programmes should raise awareness about services currently available for individuals affected by ASD such as the national autism helpline and communicate this information in a way that is relevant and accessible to communities in the Northern Province.
5. Educational programs on ASD should be developed within the community especially in schools, health centres and workplaces.
6. ASD-specific training should be provided to professionals that work with individuals affected by ASD to address discriminatory practices and develop appropriate methods to support individuals affected by ASD.
7. Awareness raising and sensitisation programme should be evidence-based and integrate the implementation of an appropriate monitoring and evaluation plan to ensure that programmes are run efficiently and effectively.

2.3.2. Identification, assessment and diagnosis

Early identification, assessment and diagnosis is vital for maximising the potential of individuals with ASD to optimise their potential to engage in society. However, many barriers to early identification exist including lack of awareness about ASD, denial that there may be a problem, stigma associated with approaching mental health services, and inadequate training among education and health staff to conduct appropriate ASD assessments. As such, diagnoses of ASD are often delayed to the detriment of individuals with autism and their carers. Population screening is also not recommended for autism. As such, this policy recommends that systems for identifying, assessing and diagnosing ASD should be well integrated into the extensive early childhood surveillance systems for developmental delay in both the public health and education systems in Sri Lanka.

Identification

Recommendations

1. Clear referral pathways for identification, assessment and diagnosis specific to the capacity of each district should be developed through the consensus of intersectoral stakeholders.
2. Protocols for routine well-baby checks, childhood developmental monitoring and school health inspections should include surveillance for red flag signs and symptoms of ASD.
3. Pre-school staff should be aware of the key developmental milestones and should conduct surveillance for signs of developmental delay including those specific to ASD.
4. Parental concerns regarding their child's development should always be respected and opportunities for parents to interact with health and education staff should be made available.
5. Red flags identified during routine well-baby checks, childhood development monitoring or pre-school surveillance should be referred to services where a medical specialist is available.
6. Professionals in roles that are likely to be the first-point-of-contact in identifying ASD should be able to identify signs and symptoms of ASD in children and adults and refer to appropriate services for further assessment.

Assessment

Recommendations

1. A comprehensive assessment that documents the individual's strengths and needs should be carried out by a qualified and multidisciplinary team, such as but not limited to speech therapists, occupational therapists, and physiotherapists with the requisite skills and experience, sharing information to build an assessment profile for each individual.
2. The assessment of individuals with suspected ASD should include interviews with parents, teachers, siblings, spouses and other close contacts.
3. The assessment protocol for suspected ASD should include appropriate investigation for common ASD co-morbidities.
4. Assessment should include risk profiling to identify vulnerabilities that may be exploited, hazards in the built environment, nutrition advice, sleep assessments and dental check-ups or children and adults with ASD.
5. When a developmental need or challenging behaviour is observed, interventions should start as early as possible regardless of whether the ASD assessment is complete.
6. Appropriate information and support should be provided to individuals suspected of having ASD and their close contacts throughout the assessment period.
7. Tools for the identification, assessment and diagnosis of ASD should be developed and validated in the Northern Province.

Diagnosis

Recommendations

1. The diagnosis of ASD is a lengthy process based on a coordinated effort by a multidisciplinary team of specialists with appropriate expertise working closely with the individual with ASD and their close contacts and should not be rushed.
2. Diagnosis should be made by an appropriately qualified medical professional, including but not limited to a consultant paediatrician, consultant child psychiatrist or consultant psychiatrist with a special interest in ASD and/or relevant experience.
3. In the case of diagnostic uncertainty, further advice should be sought for a second opinion from an appropriately qualified medical professional.
4. Diagnostic criteria that categorise individuals with autism according to their ability should be validated locally and implemented with the consensus of intersectoral stakeholders.
5. Individuals with ASD and their close contacts should be supported and given appropriate information around the time of diagnosis including clear management options to help support the transition from diagnosis to treatment, rehabilitation and long term management.
6. Once a new diagnosis of an individual with ASD has been made, the individual should be offered outstanding investigations for co-morbidities of ASD and their siblings should be invited for assessment for ASD.

2.3.3. Learning and education

Individuals with ASD face many barriers to accessing learning and education opportunities. This policy aims to overcome and mitigate these barriers to ensure that individuals affected by ASD, at any developmental stage, are provided with equal opportunities to actively partake in all educational and learning experiences. In particular, it is important to acknowledge and introduce targeted strategies to address the learning and educational needs of adults with ASD that are typically more difficult to meet once adults have left formal education.

A multidisciplinary and inclusive approach including relevant professionals, carers and individuals with ASD should be employed in providing support for individuals affected by ASD. There is a need for more ASD-specific training for professionals, carers and support givers in Sri Lanka. This training should build the capacity and competencies of relevant stakeholders in equitably supporting the needs of individuals with ASD and facilitate knowledge and skills development to maximise potential. Additionally a transitional system of services and support should be implemented to manage various periods of transition for individuals affected by ASD.

Educational needs assessment

Recommendations

1. Individuals with ASD should be empowered to participate in the assessment of their educational needs and all decision-making processes about them according to their ability.
2. Parents and carers should be treated as valuable partners and encouraged to play an active role in identifying children's education needs and devising management plans from a wide range of intervention packages.
3. Identification of the education needs of students should be conducted by a multidisciplinary team including professionals such as Special Education Needs (SEN) teachers, special education in-service advisors, occupational therapists, speech therapists, psychiatrists and paediatricians and communicated through the formulation of a Statement of Educational Needs.

Educational interventions

Recommendations

1. Based up the Statement of Educational Needs, an Individual Education Plan (IEP) should be formulated collaboratively by the SEN educator, student with ASD and parent/carer for each student to clearly communicate educational needs, teaching strategies and targets that are suitable for the student.
2. The IEP should be developed in accordance with the student's social, cultural and economic background.
3. The IEP should prioritise inclusive education over non-inclusive education.
4. The IEP should prioritise spontaneous communication and socialisation skills development over strictly adhering to curriculum-based learning.
5. The Statement of Educational Needs and IEP should be reviewed and updated periodically and shared with the individual with ASD, support-givers and carers without breaching confidentiality.

Educational support

1. SEN professionals should able to identify and support students with ASD, be proficient in autism-based teaching methods and promote inclusive practices.
2. The training for SEN professionals should include evidence-informed teaching methods that are creative and focus on advancing and developing language, communication, problem solving, critical thinking and social skills.
3. The training for SEN professionals should deepen understanding and awareness about ASD, be proficient in and be regularly updated to cover new advancements.
4. A supportive learning environment should be designed to meet the needs of students in preschools, primary schools, secondary, tertiary and vocational education institutes.
5. Transitional support should be implemented to ease transition between different educational settings and levels and the transition of young adults with ASD to adulthood and include opportunities for continuous learning.

Continuous learning

1. Vocational training centers with the necessary adaptations to accommodate the needs of individuals with ASD should be available for post-secondary education.
2. A comprehensive resource center that meets the needs of those affected by ASD should be available in each district for both children and adults affected by autism and other interested persons for furthering knowledge and skills development.
3. Opportunities for learning and involvement in social and leisure activities should be promoted and provided.

2.3.4. Treatment, rehabilitation and long term management

It is important to recognise and implement appropriate interventions for individuals with ASD at the earliest opportunity. A multidisciplinary approach should be adopted with the goal of enhancing functional development, developing skills for independent living, and minimizing stress on the individuals affected by ASD. Rehabilitation services are essential to optimise the functional level and well being of individuals with ASD and should be tailored to individual needs and strengths. A significant number of individuals with ASD need a supportive environment where long term community care is provided with appropriate supervision to allow for individuals with ASD to maximise their quality of life.

Treatment

Recommendations

1. Treatment plans should be implemented once an assessment has been conducted under the guidance of specialist consultant.
2. Liaison with a multidisciplinary group of stakeholders such as speech therapists, occupational therapists, and physiotherapists should be leveraged and facilitated through information sharing.
3. Treatment plans should be comprehensive and address needs such as behavioural, sensory, communication, educational, dental, medical, psychological and health in general.
4. Treatment and follow-up of individuals with autism should primarily involve community-based interventions.
5. Individuals with autism who are admitted as inpatients should be provided with appropriate care and placed in an enabling environment that recognises and protects their individual needs and the needs of others.
6. Interventions should be holistic in nature and include personal and contextual factors, and should be tailored to the individual.
7. Each district should develop diverse methods of treatment based on the strengths and opportunities to meet the needs of the district.
8. A comprehensive resource centre that meets the needs of those affected by autism should be developed in each district and this can be used for information, education, training and meeting purposes of those with ASD and support-givers.

Rehabilitation

Recommendations

1. At least one community-based rehabilitation centre should be established in each district with services able to meet the needs of individuals affected by ASD.
2. Adequate numbers of staff with appropriate skills should be provided for community rehabilitation centres.
3. Community rehabilitation centres should work collaboratively with mobile community outreach teams who support the functional level of individuals affected by ASD in their home setting.
4. Support to identify and engage in employment and/or apprenticeship opportunities should be provided to individuals with ASD.

Long term management

Recommendations

1. Each district should develop multidisciplinary community based support systems in collaboration with individuals with ASD and civil society organisations.
2. Community based support systems should allocate a named person (a case manager) to each individual with ASD with the responsibility to coordinate interventions.
3. Community based support systems should integrate mechanisms to conduct and regularly reviews the needs of individuals with ASD.
4. Review sessions should address behaviours that may pose a risk to individuals affected by ASD and provide timely interventions that may include, but not limited to safe placement and respite care admission.
5. Individuals affected by ASD should be supported to create effective and sustainable peer support networks.

2.3.5. Living in the community

The experience of an individual living with ASD can vary based on a number of factors. To facilitate skill development, integration into society and sustainable livelihoods, initiatives should be implemented to mitigate barriers and ensure that appropriate infrastructure and services are provided to assist individuals affected by ASD to flourish in the community. These initiatives should promote equitable access to opportunities and further their growth and development.

Recommendations

1. A multidisciplinary collaboration between the health, education and social sector should be employed to implement and promote evidence-based initiatives to support living in the community for people with ASD and other disabilities.
2. Appropriate programmes should be set up to support the development of social communication and practical skills with a focus on developing skills that are necessary for activities of daily, examples including but not limited to spontaneous communication, expected behaviour in work environments, cooking, social etiquette in informal social environments.

3. Programmes should support equitable access to public services for people with ASD and other disabilities, examples including but not limited to safe access to public transport services, priority parking spaces, and priority queues for those with permits, introducing designated time periods to make religious spaces more accessible for individuals with ASD.
4. There should be equitable access to recreation, play and leisure facilities that are facilitated to develop and support social relationships and communication skills.
5. Safeguarding initiatives for individuals with ASD should be prioritized and implemented.
6. Appropriate supports should be implemented to help transition into and promote opportunities for employment including individually tailored vocational training for adults with ASD.
7. Employment opportunities should be routinely monitored and evaluated to ensure they protect the rights, support the development and meet the needs of the individual with ASD.
8. Police department and judicial service officers should appropriately support and respond to people affected by ASD and acknowledge the impact that ASD has on social interaction and communication styles.
9. Financial assistance should be made available to individuals with ASD either directly (preferably) or through families and carers according to the abilities of the individual with ASD.
10. Residential care should be provided for individuals with ASD with priority given to individuals who lack appropriate housing and carers at the time of residential care allocation.
11. Long-term supported living in the community should be made available for individuals with ASD and allocated on a needs basis.
12. Research should be conducted in the Northern Province to deepen understanding of the barriers for individuals affected by ADS to fully participate in the community and the effectiveness of initiatives to facilitate integration.

2.3.6. Support for individuals, families and carers

This policy refers to family members and carers as parents, full-time carers, siblings, grandparents, spouses and people raised by parents with ASD. This policy also recognises that changes to a family unit mean that there may be other family members or carers whose needs should be considered. The needs of the individuals with ASD and those who share their lives with individuals with ASD in a personal capacity are complex and extensive. In light of the high variability in the way that ASD affects individuals, support provided should be tailored to individual needs. Unfortunately, these needs are often dismissed resulting in suboptimal care being delivered for individuals with ASD and avoidable stress and burnout in families and carers.

Recommendations

1. Individuals with ASD, families and carers should be provided with information about ASD in an accessible format, pre-natal counselling for family planning and other counselling services to support their psychological needs, and empowered to work in collaboration with service providers.
2. Support for individuals with ASD, their families and carers should be provided based on the needs identified through a recent, comprehensive and multidisciplinary needs analysis.

3. Support for families and carers should be accommodating and provide employment related-support, such as but not limited to opportunities for job transfers, accommodating schedules and paid leave.
4. Information regarding the results from needs assessments and subsequent plans formulated should be shared between multidisciplinary stakeholders including professionals, individuals with ASD, families and carers to facilitate effective collaboration.
5. Financial assistance should be made available to support the implementation of home-based supports, including but not limited to occupational therapy and physiotherapy equipment.
6. Education and peer support networks should be established for individuals with ASD, their families and carers, with support provided for advocacy movements to grow from these networks.
7. Overnight and day respite services should be provided for individuals with ASD, families and carers.
8. A monitoring system should be implemented to ensure that support is appropriately delivered and basic safety regulations are adhered to.

2.3.7. Professional development

Working with individuals affected by ASD can be very rewarding but also challenging. Professionals who work with individuals affected by ASD need specialist training and adequate exposure to understand the condition, empathise with the people whose lives it affects and ability to carry out their professional duties to support those affected by ASD. These professionals include, but are not limited to, public health midwives, SEN teachers, child protection officers, allied health professionals, social workers, doctors, police officers and preschool teachers. However, there is a shortage of such professionals.

Recommendations

1. All relevant professionals should receive the appropriate safeguarding checks and training in safeguarding to ensure that they are qualified and able to promote the wellbeing of individuals with ASD, particularly children.
2. Decision makers in the health and education systems should appoint appropriate health and education specialists to meet the needs of individuals affected by ASD.
3. A second tier staff force who could deliver a variety of multidisciplinary inputs to children with ASD should be created and appointed.
4. Retention rates and job satisfaction of professionals working with individuals affected by ASD should be improved.
5. Curricula of training programmes linked to service provision for individuals affected by ASD should deliver ASD-specific information and offer trainees opportunities to have hands-on experience of working with individuals with ASD in centres of excellence.
6. Pre-service and in-service multidisciplinary training sessions should be provided to develop the knowledge and skills of professionals working with ASD especially including those from the police and judiciary sectors.
7. Guidelines regarding the roles and responsibilities of professionals working with individuals affected by ASD should be developed, implemented and monitored.

8. Professionals who work with ASD should have time allocated in their work plans for continuous professional development, observation, supervision and skills-relation quality assessment of their professional practice to ensure practices align with current developments.
9. Comprehensive resource centres that meet the needs of people affected by ASD and opportunities for distance-learning should be provided to enable professionals to expand their knowledge and skills for working with ASD.

2.4. Implementation, monitoring and evaluation

The implementation of this policy shall be in coordination with various stakeholders at all levels of society under the joint leadership of the Provincial Ministries of Education and Health. An appropriate system will be developed for the recruitment of stakeholders and formation of committees for the implementation, monitoring and evaluation of this policy, along with the development of the terms of reference for each committee. Special emphasis should be made on the inclusion of individuals with autism and their carers in the decision-making processes involved in developing, implementing, monitoring and evaluating this policy. Their involvement and feedback is imperative in determining whether gaps or barriers in the implementation of this policy occur. Recommendations outlined in this policy should be translated into feasible strategies and programs in collaboration with the appropriate stakeholders.

A continuous monitoring strategy should be developed to assess whether set targets are being met and to inform any necessary adjustments to the implementation of the policy. Monitoring initiatives should be developed and implemented by a monitoring panel, comprised of a multi sectoral group of stakeholders. Roles should be developed and allocated to the appropriately qualified and trained individuals to ensure monitoring is run efficiently.

An evaluation of this policy will also be conducted to assess whether the policy is implemented as intended and the impact and effectiveness of the policy on the target group(s). An evaluation of this policy is important in determining which recommendations produce improvements and whether alternatives to relevant strategies and programs need to be considered in producing the intended impact and maximum benefit.

The design of the evaluation and indicators of evaluating will be determined by the monitoring and evaluation team. Coordination at the national level is also encouraged to develop a system for knowledge translation, where evidence-informed information can be disseminated and exchanged to promote learning and facilitate action-oriented initiatives.

Monitoring and evaluation of this policy is important for best practices and for producing evidence-informed data and research and equity-oriented development. Moreover, the implementation, monitoring and evaluation of the *Autism Policy for the Northern Province 2017-2022* will increase accountability in ensuring that the policy authentically and effectively supports and promotes the wellbeing and inclusion of individuals affected by autism in the Northern Province.